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Family-Centred Care in the Intensive Care Unit: More than just flexible visiting hours

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In this Special Issue of *Intensive and Critical Care Nursing* we are pleased to present the latest international work related to family-centred care in intensive care settings. Our journal is read in over 90 countries and the 16 articles presented in this Special Issue truly reflect the international scope and engagement in family-centred care initiatives. The contributions in this issue not only originate from across Europe, Asia, Oceania and North America, the papers also address family-centred care issues across adult intensive care, paediatric intensive care and neonatal intensive care settings.

As Guest Editors, we have been excited to receive papers reporting on family-centred care and on the initiatives being developed to improve care for families. The papers in this Special Issue explore new and emerging perspectives of family-centred care that push the boundaries of this concept. A recent international survey conducted across 40 countries identified that the most common family-centred care initiatives focus on family visitation and presence on rounds, family information, family involvement in care of the patient and family presence during resuscitation (Kleinpell et al., 2018). In this Special Issue you will read more about the impact of family visiting and family participation in care, and about other important influencers on the delivery of family care.

The interest in family-centred care has expanded rapidly over recent years and recommendations and guidelines have been published to guide clinical practice (Davidson et al., 2017; Burns et al., 2018; Gerritsen et al., 2017). Although most guidelines conclude that that quality of evidence is often low, there is a growing trend to study family-centred care interventions related to patient and family outcomes. For

example, a recent review and meta-analysis of family-centred care interventions identified 46 studies of which 21 studies tested interventions related to information, education or communication and 17 studies focussed on patient preference and needs interventions (Goldfarb et al., 2017). A variety of study designs were used across these papers including pre-post intervention design, randomised control trial and cluster randomised trial designs; reflecting the complexity of evaluating family-centred care in practice. Perhaps not surprisingly, this Special Issue of family-centred care in the intensive care unit (ICU) also includes a variety of studies using various methods and designs. However, what brings the papers together is that all authors have placed families at the centre of care and recognised the importance of family members. In bringing this Special Issue together we have been mindful of this and, in recognising the importance of families, a family member is co-author in the Guest Editorial (Davidson and Strathdee, 2019).

Various studies in this Special Issue have investigated stress, needs, and experiences of family members in the ICU. Colleagues from Norway have explored family distress in a longitudinal study up to 12 months post ICU and identified that family members reported high levels of post-traumatic stress during ICU admission but that these decreased after 6 months (Alfheim et al., 2019). The level of hope among family members seemed to be associated with levels of post traumatic stress. The authors recommend that clinicians must support family members' hope by working towards a family-nurses relationship based on trust and encouragement. A mixed method study from Australia using the Critical Care Family Needs Inventory and interviews to assess the needs of families of general and trauma ICU patients identified that families of trauma patients have different needs compared to general

ICU patients (Mitchell et al., 2019). In their qualitative analysis, the needs of families of trauma patients were thematised in Personal Distress and Adjustment, Guidance and Care. One study in this Special Issue from New Zealand explored the experiences of family members post ICU when a relative had a prolonged critical illness (Minton et al., 2019). Findings suggest that ICU clinicians need to understand the specific experiences of family members and that individual family-centred care support should be provided.

Another study on family-centred care in the ICU included in this Special Issue explored the impact of family and the relationship with ICU staff during end-of-life care. The Australian study by Butler et al. (2019) in the paediatric intensive care unit identified that when ICU staff welcomed parents into an open environment, parents felt more respected as an equal in their child's care.

Family-centred care in neonatal intensive care units (NICUs) has been well implemented in many countries. However, the study by Dall'Oglio and colleagues (2019) identified variability of family-centred care practices in 46 Italian NICUs. A Canadian team of NICU researchers went a step further as a result of exploring health care providers' perspectives on family-centred care and recommended that staffing models should be optimised to deliver responsive family-centred care in a demanding NICU environment (Benzies et al., 2019). Adopting proactive family-centred interventions was studied in a participatory action research in a NICU in the UK. Two clinical practice changes related to family-centred care interventions were implemented: improved skin-to-skin contact and unlimited parental presence at the bedside (Skene et al., 2019). Irrespective of what family-centred care interventions

are implemented in NICU, involving parents in care of their infant is an important consideration as it can decrease length of stay or increase parent satisfaction as reported in a systematic review in this Special Issue (Segers et al., 2019).

Parental involvement in the care of children in the paediatric intensive care unit (PICU) is another focus in this Special Issue reflected in three studies. The study by Craske et al. (2019) from the UK documented that parents can positively contribute to clinical assessments of their child's withdrawal of sedation and that a nurse-parent partnership can have mutual benefits in this area of practice. Another mother–nurse partnership programme in the PICU was tested in the Republic of Korea (Uhm and Kim, 2019). The programme was based on components of information sharing, negotiation and participation in care and showed positive benefits to some parent reported outcome measures. The study by Hill and colleagues (2019) from the USA implemented family-centred care in the PICU and identified that the physical and cultural environment of the PICU can impact on parental distress.

A further study included in this Special Issue addressed the specific topic of family-presence during resuscitation. A multi-country study from Poland and Finland looked at the preferences of family members regarding witnessed cardiopulmonary resuscitation (Sak-Dankosky et al., 2019), an initiative that is not widely adopted across many ICUs in the world (Kleinpell et al., 2018). The study by Sak-Dankosky et al. (2019) addresses the gap between the family wishes and how ICU nurses might become more engaged in supporting family members wishing to be more involved in the care of their loved one at this critical time.

Some novel family-centred care interventions have been tested by colleagues in Sweden and Denmark and included here. In a pilot study, colleagues from Sweden implemented nurse-led health promoting conversations with family members in the ICU (Agren et al., 2019). This intervention is expected to prevent family ill-health and promote family functioning and well-being. Another intervention from Denmark evaluates the 'recovery programme'; three consultations with patients and relatives at 1-3 months, 5 months and 10 months (Bohart et al., 2019). Reporting the negative results from this study highlights the need for specific interventions and instruments to be developed that are tailored to address individual family needs and to measure such nuances.

Finally, after the empirical papers exploring family-centred care, two methodological papers are included in this Special Issue. These focus on developing outcome measures to be used in studies testing a family-centred care intervention. One study from Sweden developed and tested the Swedish Family Satisfaction Intensive Care Questionnaire (Thermaenius et al., 2019) and a study from Turkey validated the Turkish version of the fathers' support scale: NICU (Turan et al., 2019). Although these studies are country-specific, the approaches can be important for other researchers in the field of family-centred care to consider in order to increase the number of rigorously developed and tested outcome measures.

This Special Issue has been nearly two years in the making. During this time, it has been a privilege for us to read the work of our colleagues and to learn from their research. This collection of papers re-enforces the importance of partnership working, information and sharing in family-centred care. The need for subtle

appreciation of the unique and complex family experience is also emphasised. This understanding must: influence how families are supported in practice; inform areas for further exploration; and transform design of future outcome measures. We hope that this Edition gives readers an opportunity to reflect on their own practice and consider how family-centred care can be further imbedded into day-to-day care.

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